

**Submission to Department of Social Services on**

**National Disability Insurance Scheme (NDIS) Discussion Paper:**

**Ensuring a strong future for supported employment**

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1. **Introduction**

I represent people who have Prader-Willi Syndrome (PWS), their parents and supporters. Many people with PWS struggle with employment opportunities and depend on supported employment to contribute to a meaningful life. We welcome the opportunity to contribute to this very important consultation[[1]](#footnote-1) at the invitation of the Department of Social Services, Canberra.

I will provide a general explanation about PWS to improve your understanding and respond to the specific issues and questions raised in the Paper, from the PWS perspective.

Prader-Willi syndrome (PWS) is a rare, life-threatening condition. It is a complex, multistage genetic disorder affecting multiple systems in the body. It significantly impacts on behavior, learning, mental and physical health. Adults with PWS exhibit high anxiety, complex and at times challenging behaviours and cognitive dysfunction throughout their lives. They have poor judgement and are socially isolated. Whilst they have variable intellectual disability, they all have significant cognitive and functional impairments. A defining feature of PWS is compulsive over-eating.

*‘BEST PRACTICE GUIDELINES FOR STANDARD OF CARE IN PWS’ have been published, for use internationally. More successful outcomes are achieved when service providers, educators and others adopt the specialist skills and techniques needed to support people with PWS*

People with PWS typically die young, due to complications associated with obesity. *However,* when PWS is managed properly, people with the condition can be expected to lead a more ordinary life and live longer. They will need some level of support in whichever employment setting they join.

1. **Purpose**

The feedback provided in this submission refers to the needs of adults with PWS when they enter an employment setting. The employment may be supported, open or volunteer. In any of these settings, the person with PWS will do better if there are arrangements in place to address any behaviour or food access risks. It is noted that the Discussion Paper has recognised that very few people with intellectual disabilities can take advantage of the Disability Employment Service (DES) but many can participate in Australian Disability Enterprises (ADE). This pattern would also be representative for those with PWS.

1. **Response**
   1. *Are there other principles, which should guide the Government’s policy direction for supported employment?*

The PWSA is in general agreement with the principles. However, the following clarifications are put forward.

The stated principle of ‘employment first’ needs to ensure the inclusion of the ADE model of supported employment as an option. The NDIA funding model has to be designed so that these organisations can continue to operate as viable entities. This could best be achieved by the NDIA block funding a baseline amount to each service to enable them to plan more effectively, innovate, pay for capital and running costs such as utilities and to grow. There are also non-face to face administrative costs associated with Participants, such as liaison with other supports for holistic service provision, that must be adequately funded. Growth cannot take place if there is an unpredictability in the number of participants who might join that ADE workplace. Ensuring that ADEs remain viable, especially during this transition period is critical. Therefore, block funding should be made available for at least ten years, identified in the Discussion Paper as the period for the NDIS market to reach full maturity. The rest of the ADE income would be derived from Participants.

If there are no ADE’s, the choice of employment options for people with intellectual disabilities will be drastically cut. This could easily result in them being left at home bored, and dissatisfied. Alternatively, they may go out into the community on a ‘passing the time’ activity. In addition, the NDIS ILC program is yet to make any headway in improving community/employer acceptance of people with intellectual disabilities. Given the above circumstances, the NDIA will be funding support worker time anyway. So, it would be better to guarantee the availability of the ADE option, by making a commitment to adequate centre-based funding, and giving those with an intellectual disability more choice, and the opportunity to work in a secure, predictable and safe workplace.

The Paper has recognised that ADEs are engaged in declining industries, ie that require low skills. As such, ADEs are rarely going to be a profitmaking venture. But to ensure they remain an option, partial NDIA block funding is an appropriate response.

Another principle regarding the need for the NDIS plan to be more responsive to changing employment support needs, the he current turn-around times for plan reviews are unacceptable, as is engaging in a whole plan review when there has been a request for only specific funding items to be changed. Participant’s needs in the ADE may change suddenly. As such, a quick Plan Review and update to the employment component will be essential to bring in any new supports needed and thereby help the Participant remain stable in their ADE role.

The PWSA is concerned that the diagram of the future employment landscape (pg 20) could be a misrepresentation. It implies that people with intellectual disabilities (ID) may disperse equally over new employment models. The implication is seen as flawed by the PWSA for two reasons. One is that there is currently a high proportion of people with intellectual disabilities working in ADE’s even though the DES was available. They were unable or chose not to get open employment. Members of the PWSA have reported that their adults have rarely been accepted in the open workforce. Secondly, there is anecdotal evidence from DHHS Victoria that their clients who have in the past worked in open employment are losing those jobs as open workplaces becomes faster, smarter and more complex. Even more reason to guarantee the retention of ADEs as demand is likely to continue.

* 1. *What is a ‘good’ participation outcome for a supported employee and how can good outcomes be measured?*

A good outcome for a person with PWS would be the same as for anyone else. Satisfaction with the job is a good outcome. Improved skills, confidence and social connections are other good outcomes. Greater economic participation and financial remuneration are also preferred. Important for people with PWS are also health maintenance or improvements, and behavioural stability. These later two outcomes need specialised supports. Continuity in the preferred setting is another important measure, particularly if it applies to open employment. All these can be delivered effectively in an ADE setting. Measurement can take a variety of forms, from verbal feedback, to surveys with objective measures such as wage level or health indicators.

* 1. *What do supported employees most value about working in an ADE?*

The model of integrated employment and support provision works well. There is a risk that if the two services are fragmented, overhead costs will increase at the expense of service delivery. People with PWS find participation in centre-based ADEs produces many positive outcomes. They appreciate the sense of purpose it gives them, the ‘ordinariness’ of going to work on a regular basis and the social network it provides. Such an environment supports their best performance because the environment is familiar, predictable and it supports a number of the complex characteristics experienced by people with PWS.

In addition, people with intellectual disabilities find it hard to navigate the NDIS. That is, they do not have the cognitive skills to choose, control, performance monitor, recruit and pay service providers. They are at risk of receiving poor service, either by accident or by design. Typically, a family member or other advocate takes on that administrative burden. Therefore, to have an integrated service, as offered by the ADE’s is valuable option for the participant and reduces risk, their stress and confusion.

The writer has visited several ADE’s in Germany where 100% of people with PWS that are supported by their organisation are considered to be ‘employed’; the individuals either have open employment or work at ADE’s, rather than attending ‘day programs’. This varies enormously to our Australian experience where around 7% of adults with PWS are currently employed full-time, 21% part-time and 60% participating in day programs.[[2]](#footnote-2)

* 1. *Why do most supported employees transition back to supported employment from open employment?*

The PWSA believes there are a number of reasons why people with intellectual disabilities prefer and benefit from supported employment, particularly in ADE’s:

* Co-worker acceptance and inclusion is greater
* Multiple support types can be delivered in a one environment
* Friendships can be made and retained, extending into social activities outside work, which are less likely to happen for this cohort in open employment
* Supervisors are better trained, more tolerant and more aware of the complex nature of the PWS disability
* Flexibility in adaptation of work tasks to suit individual worker capabilities
* The predictability and strict routine of the ADE workplace reduces anxiety levels that often come with the unpredictability and change in less structured work places
* Administration tasks related to ‘being an employee’ are less onerous
* Employer more inclined to helps workers to learn from mistakes rather than sacking; devote more time to ensure successful outcomes
* Task accomplishment is more tangible
* Staff more likely to pay attention to ‘the person’, not just ‘the employee’
* The work environment and fellow participants are less critical of individual idiosyncrasies
  1. *How can more supported employees be provided the opportunity to choose open employment?*
* Employers and co-workers must be more tolerant and inclusive, tasks and behavioural expectations must be more adaptable. It will require a change of mindset of employers and co-workers who must focus on what the person can do rather than what he cannot do. Self- fulfilling prophecies of failure on the part of the employer and co-workers are the biggest stumbling block to successful participation in open workplace.
* Participants with PWS need longer periods of support to bed down new routines and skills. The support needs to be in place until the skills are consolidated. Early removal of the support is the main reason that open employment fails. Gradual removal of the scaffolded support is preferred to sudden withdrawal of all support.
* The physical environment in some cases will require modification and the extra costs are often a deterrent to the employer accepting the participant with PWS as an employee.
* Considering that all the above will impact the business owner’s financial ‘bottom line’, some kind of financial subsidy to the employer could also open up opportunities.

* 1. *Why is participant access to concurrent DES and ADE support services so low?*

Members of the PWSA report that people with PWS have tried using DES without success. For example, participants have been asked to repeat ‘courses’ of which they have no need, like resume writing when they already have a current resume. The participants are left with a sense of not being heard and that the employment officer is just ‘going through the motions’. The employment officer has offered very little value in terms of finding vacancies, nor facilitating sustained employment after a job placement has commenced. There is no liaison between the ADE and DES. Liaison would provide a more holistic service for the person with the intellectual disability, who is not able to make good employment related judgements nor follow through on all the administration involved with securing a job.

* 1. *What is the role a supported employer can play in building employee capacity for transition to open employment?*

A supported employer could:

* Build task and process skills
* Build acceptable social skills, to avoid ridicule in open employment
* Train person in the administrative processes needed to be an employee
* Building social resilience in the employee
* Enable an employee to work part time in both the supported environment and the open environment, over a period, to build confidence and provide a safety net
* Retain social contacts for the employee who may move on with ambivalence
* Build knowledge of employment options that approximate the employee’s ‘dream job’.
* Manage expectations: A dream job is unlikely to be the first job. There can be a variety of ‘stepping stone’ jobs along the way, that build skills and networks
* Give the employee confidence and evidence that the ‘scaffold’ of variable supports is in place in any new work environment.
  1. *What will attract NDIS participants to employment opportunities in the future?*

PWS participants are attracted to employers who:

* Offer a job they are interested in
* Patient, kind and inclusive and safe workplaces
* Are supportive and tolerant
* Make sure other employees do not bully or ostracize the NDIS participant
* Potentially offer a social component to the employment arrangements
* Spend time to explain the tasks in easy to understand language and address any misunderstandings-monitor progress and adjust support accordingly
* Ensure there is ‘a bridge’ available to other supports if needed immediately (eg a carer to come and collect worker if they are feeling emotional or demonstrating moods that are known to lead to ‘behaviours of concern’)

To improve your knowledge about the employment needs of people with PWS, the association has created resources to educate employers. These can be found on our website at <http://www.pws.org.au/supported-employmentday-service-guide/>.

* 1. *How are ADEs marketing their services to an expanded market of potential NDIS participants?*

Unknown.

* 1. *What is the range of NDIS supports that ADEs currently offer?*

The PWSA is unfamiliar with the items on the NDIS price list for employment related supports that may be reflected in ADE service catalogues. However, given the popularity of ADEs, the NDIA should make sure they are adequately funded into the future, so that they remain as a viable option. The kind of supports that have been provided in the past and have proved effective in getting the engagement of intellectually disabled employees are:

* Building pre-employment knowledge of all the participant’s support needs
* A great worker induction and trial period,
* A physical environment that suits all abilities
* Availability to liaise with other supports outside the employment setting, as part of holistic support arrangements so that the employee has the best chance of success
* Multiple support types delivered in a one environment such as:
  + Administrative support (eg form explanations and filling)
  + Administrative advice (eg where to go to get relevant welfare help, like DHS)
  + Health maintenance support (eg diabetes monitoring or food security supports)
  + Inclusiveness by staff (eg no idiosyncrasy is too weird)
* Facilitating social opportunities apart from the work day
* Providing a venue where the participant can meet the same people every day (as many ordinary workers would), which often builds friendships that can be retained
* Adaptation of work tasks to suit individual worker capabilities and changing support needs
* Supervisors help workers learn from mistakes rather than sacking them
* Staff know the worker as an individual, not just ‘the employee’, providing moral support in stressful times
  1. *What costs would be involved for ADEs that choose to:*

*a) reform to more open employment models?*

*b) redevelop as service providers offering other NDIS supports?*

*c) specialize in the provision of employment support as a non-employer?*

The PWSA is unable to comment except to say this:

* People with cognitive impairments need a lot of support that is not face-to-face. As such, the NDIA must make funds available in all employment models to cover those non-face-to-face expenses that will be incurred by providers.
* Any reform and redevelopment by providers will logically incur unusual costs. ADE providers are typically not-for-profit organisations. As such, they do not have large reserves of cash for research and development. Not only that, the NDIS transition period is already putting new financial pressures on those organisations. The NDIA needs to provide supplementary funding, not tied to individual participants, to allow for new and experimental employment service models to develop.
  1. *Should the Government have a role in supporting new market entrants and start-ups in the short-term?*

The government (or the NDIA) should provide funding for not-for-profit to investigate new employment models. Money is best invested in organisations that have proven experience helping the disadvantaged. They can then employ innovators, so the best of both skill sets is brought to bear without the risk of sharp operators taking funds with little outcome, as has happened in the VET sector.

Private providers could be in a conflict of interest with any incentive money. They are sometimes driven more by profit opportunities than by any steadfast values about improving employment outcomes for the disadvantaged.

* 1. *What investment, or industry adjustment will promote viable expansion in the employer/provider market?*

Any investment needs to provide a reliable baseline of funding, whilst the NDIS market place transitions and matures. The NDIA must be careful not to let smaller and niche services fail.

* 1. *How could employer/providers share learnings of their success and failures within a competitive market?*

At minimum, participants and their nominees should be able to transparently see the performance of providers and supported employers, say via the NDIS portal. That way, the participants would have more choice and control, as well as successful and unsuitable practice brought to light.

* 1. *How can wage supplementation be better targeted?*

Employees in ADE’s would welcome a fairer wage.

There would need to be better regulation of any supplement than in the past if used in the private sector. Prior employment incentive schemes saw some employers having a ‘revolving door’ of disadvantage employees who were dismissed after the wage subsidy ran out and substituted for another.

* 1. *How can the NDIS enable an employment first approach in planning?*

The NDIS needs to recognise that a variety of employment options must be available for people with PWS. People with PWS who work in supported or open employment rarely, if ever work full time (38 hours/week) due to their disability. People with PWS also suffer from severe anxiety and need to get used to new situations gradually. Hence, even though some may have the ability to eventually work, say 15 hours per week, the buildup of tasks and hours would need to be taken one small step at a time.

* 1. *How do current assessment processes drive the inclusion of employment supports in an NDIS participant’s plan?*

The PWS participant can express their employment goals in their plan. In addition, the person may already be working in a supported arrangement when the plan is commenced, and current status forms part of the assessment. It is unknown whether the NDIA takes into account the DMI.

1. *Are existing employment assessment processes appropriate for NDIS participants?*

People with PWS have a multi-faceted disability. As such, the provision of multi-faceted supports in the ADE style workplace are very beneficial in supporting those with PWS to enjoy economic participation. It will therefore be essential that the NDIA Planner take into account a DMI type assessment when creating the employment component of the Participant’s NDIS package. The former Disability Maintenance Instrument (DMI) seems inadequate, because it did not reflect hours in the workplace. However, the NDIS funding should address both the intensity of service needed, plus the length on any given day.

* 1. *Are there different approaches to planning that could be explored for different groups of supported employees (e.g. younger workers, established workers, retirement transition)?*

For younger workers, a transition to work may be supplemented by TAFE courses. This more closely reflects the ordinary life of a young adult. For older cohorts, off-site TAFE may not seem attractive. Established workers may prefer training courses that are brought into the workplace.

1. *How could SLES better support school leavers to build skills and confidence in order to move from school to employment?*

Additional funding within NDIS plans could be made available to final year school students to facilitate improved transition from school to employment. In our experience, most individuals have received minimal transition support due to a lack of resources within their school. Meaningful transition implementation is likely to require trained one-on-one support in future employment settings, that increases in regularity as the school year draws to a close. The writer is currently researching such a program at the Latham Centres, a school that specialises in educating children with PWS, located in Massachusetts, United States.

* 1. *What role could or should an NDIA Local Area Coordinator or planner have in linking participants to an employment opportunity?*

To date, the PWSA has not seen either NDIA Planners or LACs with the time to properly manage plans or plan reviews. The recent NDIA report on improving the participant experience[[3]](#footnote-3) heralds that planners and LACs will be spending more time with participants to get planning and reviews right. It therefore seems premature to expect them to become employment experts as well. Such an activity may be better performed by a Support Coordinator, especially one that had a focus on employment. It is important that any role designated to help the disabled person with employment knows the person and has an ongoing relationship with them. It takes time to find a job, and job maintenance is also likely to need an NDIS Support Coordinator to get the right balance of employment specific supports into place.

* 1. *What role could or should NDIA market stewardship have in developing a market with a range of employment, other support, or participation options for existing supported employees?*

Firstly, the NDIA must ensure that existing supported employees are no worse off under the NDIS. If those employees had ADE employment, that service must be maintained, via subsidy if necessary, until another, more preferred option becomes available for those participants. And in order for other options to become available, it would be appropriate for the NDIA to take a strong role. This could include:

* Locate opportunities for alternative models
* Foster opportunities
* Tightly regulate any funds released
* Monitor and evaluate any new models
* Ensure transparency to participants about what has been funded, the expected outcomes, and how each new service is going
* Ensure options are always realistically available for those with intellectual disabilities

1. **Conclusion**

People with PWS have aspirations to work in a variety of fields of employment. People with PWS need to be purposefully occupied during the working week, as an ordinary person would. However, experience has shown that it is very difficult for a person with PWS to hold down a job in the open market. The literature about this complex condition explains that it is important for people with PWS to be occupied or their welfare will be compromised, as may that of their carers. Supported employment is a good option as either a stepping stone or as a worthy and satisfying alternative.

The PWSA is therefore very supportive of the NDIA being actively and financially involved in ensuring that ADEs are not forced to close under the NDIS. This would be contrary to the policy of choice and control for the intellectually disabled. The PWSA agrees that it is important for the NDIA to facilitate the development of other supported employment models as well, to complement the ADEs. I am happy to discuss these issues further at your convenience.

James O’Brien

1. The Discussion Paper was available from the web page <https://engage.dss.gov.au/the-future-of-supported-employment/a-strong-future-for-supported-employment-discussion-paper/> [↑](#footnote-ref-1)
2. Prader-Willi Syndrome and the National Disability Insurance Scheme, A report by the University of Melbourne for the PWS Better Living Foundation Ltd with assistance from the Prader-Willi Syndrome Association of Australia. 12/1/2015 [↑](#footnote-ref-2)
3. <https://www.ndis.gov.au/medias/documents/pathway-review-report/Report-NDIS-Pathway-Review.pdf> [↑](#footnote-ref-3)